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# **Towards a pain free hospital: An in-depth qualitative analysis of the pain experiences of head and neck cancer patients undergoing radiotherapy of head and neck cancer patients undergoing radiotherapy**

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## **Abstract**

### **Background:**

Treatment for head and neck cancer can frequently be a painful experience with implications for patients in terms of quality of life, nutrition and ultimately treatment outcomes. Pain may arise for a number of reasons in this patient group including the influence of localised tissue damage from radiotherapy, the effects of chemotherapeutic agents as well as the disease process itself. Early identification of cancer pain, through screening and early analgesic and pain management are thought to be the most appropriate approaches to the problem.

### **Aim:**

To explore in-depth, patients' views of the experience of pain related to radiotherapy for head and neck cancer, within the context of a randomised controlled trial (RCT) of pain screening and intervention.

### **Sample:**

A purposive sample of head and neck cancer patients undergoing radiotherapy who were participating in a separate RCT of a proactive pain screening intervention.

### **Methods**

A qualitative design using one-off, face-to-face, in-depth interviews. Data were inductively analysed for themes using thematic analysis. Data were collected from September 2012 to January 2013.

### **Findings**

Eight participants were interviewed. Several issues around pain management arose and the influence of various factors became apparent. Four dominant themes emerged; *facets of radiotherapy pain in head and neck cancer, facilitators and barriers to pain management, pain services* and finally *interdisciplinary working*.

### **Conclusion**

The specific issues faced by head and neck cancer patients undergoing radiotherapy highlight the need for pain relieving interventions delivered by pain specialists, in tandem with the development of robust self-management strategies. An integrated approach to care is optimal, comprising pain screening at each outpatient encounter, and review by specialists as necessary.

## **Background**

The incidence of head and neck cancer is increasing, with over 550,000 new cases diagnosed worldwide each year <sup>1</sup>. This is thought to be related to a number of factors including rising alcohol and tobacco consumption and increased sun exposure.

Head and neck cancer is an umbrella term for a variety of malignancies including those of the oral cavity, lip, throat, middle ear, sinuses and salivary glands. Their aggressive, erosive nature and the rich sensory innervation of this area mean that these comprise some of the most painful cancers <sup>2,3</sup>. Van den Beuken-van Everdingen's 2007 review of 52 studies spanning fifty years and including over 8000 patients places the prevalence of cancer pain at greater than 50% with the highest prevalence in head and neck cancer patients (70%)<sup>4</sup>. In terminal head and neck cancers, the prevalence of pain increases to as much as 77% <sup>5,6</sup>.

Specific reasons for the high prevalence of pain in head and neck cancer relate to both the treatment adopted and the pathophysiology of the primary tumour itself. This includes direct invasion of bone, cancer infiltration of nerve roots, trunks or plexuses, regional metastases, infection, ulceration and inflammation <sup>7</sup>. In addition, pain related to surgery or chemotherapy and importantly, radiation-induced mucositis often account for treatment-related pain <sup>8</sup>. Radiation-induced brachial plexopathies also play a role in causing pain in this population <sup>9</sup>.

Cancer pain is a significant issue and its treatment is often sub-optimal, leading to wide-ranging adverse effects on patients' quality of life <sup>4,10</sup>. Under-treatment may occur for a number of reasons, with causative factors related both to attending health care professionals and the systems they work in and to the patient, their family and the society they inhabit <sup>11</sup>. These factors predominantly relate to poor screening or assessment of pain, inadequate knowledge and prescription of analgesia, and poor opioid side-effect management <sup>12</sup>.

Long-term, head and neck cancer pain impacts adversely on quality of life, with substantial pain persisting beyond five years in one in six survivors <sup>13</sup>.

## **The Qualitative study**

### **Background to the study: screen and treat trial:**

The participants recruited to this qualitative study were concurrently involved in a distinct randomised controlled trial (RCT) of a pain screening and management intervention for head and neck cancer patients<sup>14</sup>. The programme of care received by

participants randomised to the intervention limb of the study is outlined in box 1. Participants randomised to the control limb received 'usual care'; proactive review by the pain team was not organised unless a meeting was specifically requested by either the patient or their oncologist.

## **BOX 1**

### **Objectives**

The overall objective was to explore patients' in-depth views of the experience of pain related to radiotherapy for head and neck cancer, with two further specific objectives:

- To explore patients' experiences of a 'screen and treat' system, within an RCT
- To gain in-depth knowledge of any barriers to analgesic control within this population.

### **Methodology**

#### ***Study setting and approval***

The study was conducted in a specialist oncological hospital. Ethical approval was granted by the local Research Ethics Committee. Written informed consent was obtained from participants. In-depth interviews were conducted over a five-month period from October 2012-January 2013. The qualitative sub-study formed part of a larger study and RCT: Towards a pain free hospital, funded by the National Institute for Health Research (Grant number PB-PG 0808 16260).

#### ***Study Population & Sample***

Qualitative studies seek in-depth insight in order to understand the experiences and points of views of participants <sup>15</sup> . A purposive sample was drawn from patients with head and neck cancer, undergoing radiotherapy. Eight to ten participants were sought for the sample, with half from each arm of the main RCT. The sample was selected to reflect a range across head and neck cancers, experiences, age, radiotherapy treatments and gender. Inclusion criteria are detailed in box 2.

## **BOX 2**

### **Data Generation**

Data were generated through single in-depth; face-to-face semi-structured interviews. An interview guide was used as an aide-memoire (Box 3). Interviews were audio-

recorded and transcribed verbatim. Rigor and validity was ensured through team discussion and refinement of themes, ensuring emergent themes and domains accurately reflected the data. Credibility and reflexivity was further maintained through the use of a detailed field note diary, which was used to inform thematic development.

### **Box 3**

#### **Data Analysis**

Interview data were analysed using a thematic analysis framework, with themes being derived from the data, additional analysis used a coding frame based on verbatim transcriptions. These were developed using an inductive-iterative approach to analysis, based on an inductive thematic analysis, and aided by reflexive notes from the interviews <sup>16</sup>. Meaning units were collated into sub-themes and those with a similar focus were then grouped together under main themes. Data were analysed together for both control and intervention group and contrasts drawn, where appropriate, within each emerging theme.

#### **Results**

Ten patients were approached out of a potential pool of 156 participants from the main RCT and eight were interviewed, based on the sampling method described previously. Four men and four women with a mean age of 61.7 years were interviewed for between 27 and 52 minutes, away from the clinical area.

#### **TABLE 1**

Four major themes emerged from the data: *Facets of radiotherapy pain in head and neck cancer, facilitators and barriers to pain management, pain services and interdisciplinary working* (table 2). Under these domains, the main themes and sub-themes are reported, with contributing categories outlined in each section. The first two themes reported are the largest themes, with subsequent themes smaller, but still distinct.

#### **TABLE 2**

## **Theme 1: Facets of radiotherapy pain in head and neck cancer**

The first theme that emerged related to facets of radiotherapy-induced head and neck pain; encompassing sub-themes of previous pain experiences and forewarning. The pain, due to radiation-induced tissue damage and desquamation of the oral mucosa created a significant issue for all but one of the participants. All patients described pain on swallowing as the main feature.

“. . .How severe I mean to drink a drop of water it was like swallowing barbed wire. It sounds ridiculous but that's how it felt. . .” (Participant 1, control arm)

“It wasn't a sharp pain, it was just this nagging, dull pain around the throat, and it seemed to get worse when I tried to eat. . .” (Participant 4, intervention arm)

The effect of this severe pain was two-fold; it contributed to cancer fatigue, already a significant issue for all participants, and also meant that patient's oral intake was reduced. All patients, except one, required additional nutritional support and commonly naso-gastric feeding, as a direct result of swallowing pain and concomitant weight loss. Furthermore, the fact that radiotherapy took place over a period of several weeks, meant pain was prolonged.

“[It was] prolonged, significant pain. It didn't matter what period of, or what part of the scale it erm... it didn't erm.. it didn't matter what period of- or what part of the scale it was on, for a period of time that was permanent.” (Participant 4, intervention arm)

### **Previous experiences of pain (sub-theme 1)**

Many participants used previous pain experience as a reference point by which to measure their existing pain. Perceptions of current pain during radiotherapy were shaped by the severity and management of previous pain; with two participants also having experienced cancer pain (with previous diagnoses of distinct primaries). Interestingly, participants often voluntarily used numerical pain scores in the interviews to describe and illustrate pain severity, overlapping with the value of pain screening and pain scores sub-theme, described below.

These prior experiences influenced how patients sought or managed pain relief in the radiotherapy-related pain period. Specifically, experiences of their GP and previous pain shaped how they subsequently dealt with radiotherapy pain. Reports of negative experiences of support meant participants were more likely to outline a preference for

specialist pain management support. This issue is developed in the theme, *Interdisciplinary working*.

### **Forewarning (sub-theme 2)**

Forewarning of expected pain during and after radiotherapy differed, ranging from receiving warning, but feeling it made no difference, to receiving no forewarning.

“No-one actually told me, they might have said I might have difficulty but didn’t mention any levels of pain or anything.” (Participant 4, intervention arm)

“... I would think that people should be told that- that this could be painful or that could be painful- I was definitely told that swallowing would become difficult, that swallowing would become painful and that my neck would probably become sore and painful later on in the treatment and after the treatment I think that was a very important point.” (Participant 3, intervention arm)

Being told you would experience pain, did not necessarily mean anything if there was nothing to base that pain experience on.

“I didn’t know what to expect to be honest.” (Participant 7, control arm).

### **Psychological impact of pain (sub-theme 3)**

The presence or absence of forewarning did not prevent the emotional sequelae of severe pain.

“[It] got me down . . . and I was you know, losing weight and that was something that was annoying me . . . it just got on top of me. (Participant 1, control arm)

Experiencing severe pain, especially suddenly, was “very frightening” (Participant 6, control arm), despite forewarning. Participants described how pain impacted both their social-life and well-being in general, with some participants choosing not to socialise either because of concomitant fatigue, inability to eat, visible radiation burns, or because of pain.

“it slows you up completely, you can’t eat, you can’t drink properly. . .there’s nothing worse than pain is there because it totally slows you up, makes you all tired.”(Participant 7, control arm)

“I suppose I just didn’t want to see- people to see me having such difficulty in swallowing, I didn’t want people to see my neck. . . I suppose in a way I just didn’t feel that I was.. possibly a bundle of joy to be with (...) and I think that would be both the pain and the difficulty of swallowing you know.”” (Participant 3, intervention arm)



Moreover, based on these radiotherapy-induced pain experiences, there was fear that pain could return, particularly radiotherapy-related dental pain. Good communication between doctor-patient lessened the psychological impact of pain and was also evident in other themes discussed below.

## **Theme 2: Facilitators/Barriers to pain management**

Two key sub-themes emerged: reporting pain (including using scales) and the use of analgesia.

### **Barriers to reporting pain (sub-theme 1)**

Patients reporting pain encountered several issues, relating to self and personality (notably, stoicism), to communication problems, and to previous experiences, with this aspect of the sub-theme overlapping with *Interdisciplinary working*.

Stoicism in relation to pain was a recurrent issue, with patients feeling they should not share their pain. This was reflected in several accounts:

“I think you’re trying to be brave.” (Participant 3, intervention arm)

“I am the sort of person, I take it and get on with it, I do moan but I get on with it.” (Participant 8, intervention arm).

Equally, others participants described not hiding their pain and of being honest about its extent to ensure access to help managing it.

Communication was seen as a key issue in managing pain; good communication between the pain team and oncology teams, was highlighted as essential for good pain management, overlapping with the later theme of *Interdisciplinary working*.

### **Using analgesia: managing own pain with support (sub-theme 2)**

Adherence to recommended treatment was influenced by patient’s personalities, specifically their willingness/ability to engage with management plans. Participants indicated the key role patients play in successfully managing pain; specifically that following advice contributed to improved analgesia.

“I was reasonably lucky in as much as I did have pain, but what the nurses told me to do, I did and I found that it did alleviate the pain. (Participant 4, intervention arm)

Contrasting this, some patients developed their own strategies for pain control, as exemplified below:

“It’s was least 3 months before I saw my GP, and they said: ‘take Naproxen’ which I am not too keen on. Initially I took one or two ibuprofen, it doesn’t help,

so I stopped taking. Even the Naproxen doesn't help, and I know with taking them long term, you get more side effects, stomach problems and all that- so if it's not effective and I don't take them." (Participant 8, intervention arm)

Fear of analgesia or drugs in general, in terms of side-effects, or of addiction, also created a barrier to analgesic use.

"I think I have a sort of erm.. distrust of using drugs to get things to disappear completely." (Participant 2, control arm)

"Something that concerns me is about being on tablets for a long time and whether that begins to have it's own effects which then have to be coped with." (Participant 5, intervention arm)

There was however, scope for adjusting doses under the prescribing doctors' or nurses' guidance. Patients who felt comfortable managing and titrating their own analgesia appreciated approaches that facilitated this. This approach demonstrated trust between health care professional and patient, which developed as the relationship progressed. This trust was important and was fostered by good bedside manner, and an understanding that, where appropriate and with support, patients could manage their pain. One participant described how a "good bedside manner" (Participant 4, intervention arm), was important in gaining confidence. With that confidence comes enhanced patient engagement with the treatment plan, which in turn improves pain control.

### **Theme 3: Pain services**

Participants offered views on how they felt pain management services should be configured, overlap with interdisciplinary working was frequently evident. Emphasis was placed on experiences of good inter-professional communication and the effect this had on pain management. Being reviewed by a pain specialist gave many patients confidence in their pain management.

"There was a pain management person that I saw, who was very helpful and gave me a lot of information and then made sure I had all the right drugs." (Participant 2, control arm)

"During my treatment pain was paramount and I was asked about it regularly and whether I was in any discomfort during my treatment " (Participant 5, intervention arm)

#### **Accessing analgesia (sub-theme 1)**

Participants did not specifically mention any problems in accessing analgesia and talked of timely intervention.

“I was given pain killers pretty soon into my treatment. I don’t think they just started when I was admitted to the hospital. . . It (analgesia) was available for me to take to cope with the pain as much as I needed.” (Participant 5, intervention arm)

Frequency of screening was identified by some participants as important. Different views were expressed as to whether screening was needed at every visit to out-patients at the hospital or whether it should be determined on a case-by-case basis, according to severity of pain:

“I think a lot of it would depend on the patient and the severity of their cancer quite honestly.” (Participant 4, intervention arm)

Frequent assessment of pain was seen as advantageous not only for patients but also for reviewing progress:

“it enables the patient to review how they’re feeling, and report on that and it updates the team I presume on progress” (Participant 2, control arm).

Interestingly, one participant felt there was also a ‘suggestive’ element (Participant 2, control arm), by drawing attention to pain that might have otherwise not been problematic.

### **Value of pain scores for assessing pain (sub-theme 2)**

The use of a numerical pain scale as a method for screening for pain was in general, already familiar to patients, this however, did not mean that there was unanimous belief in its value. Some patients felt it accurately reflected their pain and was “helpful” (participant 1, control arm), whilst others felt the subjective nature of pain meant its value was questionable. Furthermore, the pain scale’s subjectivity emphasized how, for one participant, the change from 8/10 to 5/10 meant a shift from severe to acceptable pain.

For others acceptable pain was considered much lower: 2/10. For this participant, the pain scale was problematic:

“ . . it’s just hard to put a number on all of that and feel confident that you’ve given the best information. I do struggle sometimes- and its all- obviously everything’s relative. . .you know, what is a ten for me? (Participant 5, intervention arm)

## **Theme 4: Interdisciplinary working**

### **Who manages pain (sub-theme 1)**

For the majority of patients, pain and oncology services were viewed as operating 'hand in hand'. One participant stated that she would prefer her pain issues to be addressed solely by the oncology team; however, most participants believed that pain should be managed as a combined effort between oncologists and pain specialists. Oncologists were regarded as being valuable in identifying pain and pain specialists as more appropriate for managing and titrating analgesia.

"I can remember pain being something that my consultant (oncologist) was very keen to keep under control during my treatment when I was obviously, clearly suffering with pain." (Participant 5, intervention arm)

Referring to how the radiotherapy nurses also monitored his pain, this participant outlined how the teams worked together:

"On one occasion I did say that the drugs had taken away the pain but made me feel very sick and they immediately called the doctor to come down at the end of my treatment and see me and change the treatment." (Participant 6, control arm)

### **Role of community services (sub-theme 2)**

The role that general practitioners played in managing pain was raised by some participants. GPs were highly valued for their overall supportive care in relation to cancer treatment, but in relation to pain, they were not the preferred care provider.

"It comes down to the causes of the pain and whether it's really within the field of the GP. . . (Participant 5, intervention arm)

"If you are talking about the pain management team, they're the specialist so they might even be more aware so I would trust them to give better care than a GP. " (Participant 8, intervention arm)

Participants' experiences of how previous pain episodes had been managed shaped their beliefs about GPs' ability to manage their cancer pain. This theme demonstrated how participants recognised the value of specialty teams caring for them and their pain.

### **Discussion**

Patients with head and neck cancer have complex pain issues that impact on their treatment, general well-being and recovery. Effective pain management was seen by all participants as a key component of the post-radiotherapy recovery process. Key findings of this qualitative study are summarized in box 4.

This study found that previous pain history influenced how patients experienced radiotherapy-induced head and neck pain. This finding is reflected in several studies, with pain history being shown as a predictor of the severity of pain, especially with a history of chronic pain and pre-treatment pain<sup>17–19</sup>. What is unique about the findings in our study is that participants actively sought to manage their pain, based on prior experiences. Forewarning about potential pain and expectation management did not necessarily improve pain experiences (as might be envisioned), although it did enhance patient understanding of what was happening to them.

The detrimental influence of pain on quality of life in this oncology population has been described previously<sup>20</sup>. These findings are mirrored by our study which clearly demonstrates how pain adversely affects the quality of life of head and neck cancer patients.

#### **BOX 4**

In relation to facilitators and barriers to pain management, it was clear from the participants' responses that a unified approach to controlling pain was best. Few resource barriers to reporting pain existed. Identifiable barriers to pain management related more to patients' ability to convey the extent and nature of their pain, hindered either by stoicism, embarrassment or communication problems. The ease with which patients were able to communicate the degree of their pain is clearly of fundamental importance.

Numerical pain scales have been criticised for their bluntness and lack of specificity<sup>21,22</sup>. Participants in this study echoed that sentiment, however, as one patient stated, the very subjective nature of pain assessment is always going to limit their use. These findings related to both to behavior and the ability to express pain have implications for under-treatment, a problem identified in the cancer population<sup>23</sup>. Participants did, it should be noted, describe self-managing their pain, with ongoing support from pain specialists. This support meant a good relationship existed between pain specialist and patient, fostering the concept of 'ownership' of pain and improving outcomes. A possible response to the criticism aimed at numerical rating scales would be to consider using either a 'bother factor' or pain distress scores which permit the identification of those patients most affected by pain. This would facilitate the targeting of pain management resources to those patients at most need and obviate the use of a set numerical rating score to trigger referral to specialist pain services.

Funk and colleagues identified the key role that early pain management intervention delivered by specialist teams has in improving the long-term quality of life of head and neck cancer patients with persistent pain and reduced oral intake<sup>13</sup>. Our study reiterates Funk's findings, with participants expressing support for early, targeted pain intervention resulting in improved functional levels and oral intake.

The need for screening for pain in outpatient clinics has been documented <sup>24</sup>, but evidence for taking action based on the findings of screening is less obvious. The findings of our study illustrate the need for effective screening measures, which identify not only patients in pain but specifically, those who need to be reviewed and treated by pain specialists. Screening for pain may take a number of potential guises. These include paper based questionnaires, focused questioning at the time of clinical review or the self-reporting of symptoms using modern IT solutions such as pain related apps.

There were equivocal views amongst the participants about the role of pain teams and who should screen for patients' pain and, in certain cases, treat that pain. Some participants wished to be reviewed by pain specialists, whilst others were happy for pain to be managed by their oncologist. Pain treatment preferences were dependent on both the complexity of the pain and the presence of other complicating issues such as the need to titrate analgesia. In general when cases were challenging, participants favoured pain specialist review. GPs were not identified as being a preferred source of support in terms of managing complex radiotherapy-induced pain.

There are undoubtedly limitations to the study, with a sample that might not be reflective of this overall population. The qualitative approach and sample obviates certain generalisations, however, 'moderatum generalisations' <sup>25</sup> across broad principles that could apply to others can be taken and applied to other similar groups, such as those undergoing radiotherapy for other cancers. Future research should draw on these findings and further explore alternative pain screening approaches in larger sample populations, alongside interventions to ensure the issue of under-treatment of radiotherapy-induced pain is resolved.

## **Conclusion**

The experiences of these participants highlight the myriad pain-related issues faced by head and neck cancer patients undergoing radiotherapy and illustrate the value of interventions to relieve pain and specialist pain care. Specifically, attention paid to fostering relationships between patients and the specialist pain team helps support

patients in taking the lead to manage their own pain and analgesia. An integrated approach to care is required where all teams, no matter their clinical background, screen for pain and related distress at each outpatient encounter, and refer onto specialists as necessary. Such approaches would help to promote the concept of early intervention, leading to rapid identification, treatment and support of patients experiencing radiotherapy-induced pain.

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### **Declaration of Conflicting Interests**

'The Author(s) declare(s) that there is no conflict of interest'

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